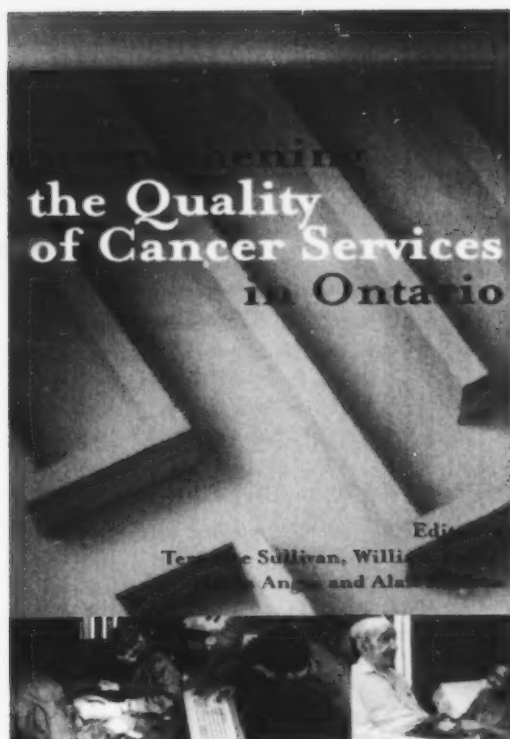


Strengthening the Quality of Cancer Services in Ontario

Synopsis



Cancer Quality Council of Ontario

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Preface

Cancer in Ontario is a leading cause of premature death and disability. Efforts to control cancer, including prevention, early detection, treatment and palliative care, make up a huge portion of the health care system in Ontario. In recognition of these facts, the provincial government announced the Cancer Quality Council of Ontario (CQCO) in October of 2002.

The CQCO was created to monitor and assess cancer system performance and drive needed improvements. In partnership with Cancer Care Ontario (CCO), the council will work towards a cancer system that is coordinated, patient-focused and as seamless as possible. The council will undertake special studies, spearhead breakthrough projects on quality improvement and monitor and report on key indicators of system performance.

The inaugural report of the CQCO is a two-volume book that describes the state of the province's cancer programs and services. Its thirteen chapters include contributions from over thirty experts in the field of oncology who address major quality issues in the cancer system. This synopsis summarizes the full report, "Strengthening the Quality of Cancer Services in Ontario", and takes stock of the strengths and weaknesses in system performance and measurement and outlines areas where improvements are needed most and are likely to have the greatest impact.

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Executive Summary

This is a synopsis of the inaugural report of the Cancer Quality Council of Ontario (CQCO). The CQCO is the first body of its kind in Canada and as such, has a unique opportunity to work with patients, cancer service providers and policy makers to improve Ontario's cancer system. The council's mission is simple: to reduce cancer incidence and improve outcomes for people diagnosed with cancer.

In 2003, an estimated 52,700 people in Ontario will be diagnosed with cancer and over 24,000 lives will be lost as a result of this disease.¹ Today, almost 150,000 cancer patients are receiving active treatment and an *additional* 300,000 individuals have been previously treated for cancer.

Even with concerted efforts to improve prevention and early detection programs in Ontario, the aging population will continue to grow and therefore, so will the number of cancer cases.² Cancer Care Ontario (CCO) is taking action against the fragmentation of cancer services by integrating cancer programs and establishing regional cancer strategies. Through the CQCO, CCO is committed to improving the quality of all cancer services by enhancing the measurement of system performance and using this information to motivate and coordinate quality improvement.

At present, there is room for improvement in the measurement of cancer system performance in Ontario. In order to understand better the current quality of cancer services and target improvement efforts, Ontario needs to:

- ✓ Remove barriers to the development of high-quality health services research.
- ✓ Improve the use of population databases.
- ✓ Expand and improve information systems to measure performance and enhance clinical care.
- ✓ Continue to develop and disseminate clinical practice guidelines, making use of a broader range of strategies to support their uptake and evaluation.

Prevention and screening are the best hope for slowing the epidemic of cancer. In the spring of 2003, the *Cancer 2020* report: *Targeting Cancer: An Action Plan for Cancer Prevention and Detection* set out an ambitious action plan for cancer prevention and detection that includes evidence based, achievable targets for changing population behaviours that affect cancer risks.³ Strategies to support the plan need to be developed, including regular public reporting of progress toward the targets.

The Canadian Task Force for Preventive Health Care Screening has recommended population-based screening for breast, cervical and colorectal cancer. In Ontario, better systems for data collection and assessment would improve existing breast and cervical screening programs and quality indicators for colorectal screening need to be developed. There is also an emerging need to enhance genetic screening services.

Cancer treatment plays an essential role in reducing the burden of cancer and there are steps that should be taken to maximize its effectiveness. Decision-makers understand very little about access to and appropriateness of cancer surgery in Ontario. Over the past decade, Ontario has experienced an increase in waiting times for radiation therapy (RT) and it is suspected that up to 20% of people who could benefit from RT do not receive it. Waiting times for systemic therapy have also increased over the same period though not as dramatically as RT. Mechanisms should be put into place to support uptake of clinical practice guidelines, quality assurance and patient safety. Broader use of physician order entry systems and standard operating procedures will make significant gains in the quality of systemic therapy in Ontario.

Finally, the *supportive care* needs of cancer patients are often overlooked. Overall, less than 3% of cancer program budgets are clearly allocated to supportive care and fewer than 5% of Canadian cancer patients have access to palliative care services when they need them. There is no doubt that a concerted effort is required to better meet the supportive care needs of cancer patients and their families. The development of performance indicators for supportive care and practice guidelines would help set expectations for care delivery.

Improving the quality of cancer programs and services cannot be put on hold while improved tracking and information systems are established. This synopsis and the full report represent an initial roadmap for making needed improvements in cancer services in Ontario. They are based on information obtained through existing sources such the Ontario Cancer Registry (OCR), the clinical information systems at CCO and other hospitals and administrative databases housed at Institute for Clinical Evaluative Sciences (ICES) and elsewhere. The authors are also grateful for the input of CCO regional cancer advisory committees about priority areas for performance improvement.

The CQCO is poised to make significant progress in measuring system performance and to provide the tools necessary to assist in management and clinical decision-making. The council has a mandate to report publicly and is expected to function impartially as it provides advice to the government of Ontario through CCO. Cancer Care Ontario will rely on the CQCO to provide objective information on system performance and quality for *all* cancer services including services beyond those currently managed by CCO.

A. Context

1. The Current Picture

Put simply, quality in cancer services means ensuring the right intervention for the right patient at the right time. However in Ontario, this goal is hindered by a large and complex cancer system that is managed by a multitude of organizations. In addition, the complex nature of the disease itself also adds to the challenge of cancer control.

a) Defining Quality

Quality of cancer care can be measured by the extent to which cancer services for individuals and populations achieve desired health outcomes and are consistent with the current state of professional knowledge.⁴ In cancer services, quality is reflected in the structure of organizations and their regulatory environments, the processes of patient care and review and, perhaps most importantly, the *outcomes* of care. From a patient's point of view, quality cancer care means unimpeded access to timely care, a positive health status and a good quality of life. From an economic point of view, efficiency and equity are also important aspects of quality.

A focus on quality includes:

- **Assessment** – an examination of the state of quality.
- **Quality assurance** – a process designed to ensure standards of quality are met.
- **Quality improvement** – an iterative process designed to strengthen quality by continuously measuring and raising targets.

b) Unique Attributes of Cancer

Unlike many other chronic conditions, cancer is not one, but a large group of diseases characterized by an uncontrolled division and growth of cells in various tissues of the human body. Cancer typically starts when the genetic structure (DNA) inside the cell is damaged or altered. Cancer cells may grow and form a mass of tissue called a malignant tumor. As the tumor grows, it damages neighboring tissue. A malignant tumor can take a long time (up to 30 years) or a short time (2-3 years) before symptoms are evident. By then, the cancer may have spread or metastasized to other parts of the body.

Cancer diagnosis requires a review of the patient's history, physical examination and additional tests. Examination of the tumor tissue and imaging of the patient's body help determine the nature of the tumor and the degree of disease spread that has occurred. The extent of disease is referred to as stage of cancer.

The course of cancer may vary depending on the disease site, biological features and the extent of disease. For example, some cancers of the breast are encapsulated and when removed may never recur. Cancer patients often require many different diagnostic procedures and treatments during the course of their illness. Many forms of cancer can be successfully treated and managed with a mix of surgery, radiation and chemotherapy regimens while others continue to have a poor likelihood of survival. In the case of the major cancers for men, such as prostate, and for women, such as breast, cancer is evolving into a chronic disease with much improved probability of survival. In many cases, cancer has become a disease with multiple acute episodes, which can be the result of recurrence or treatment complications.

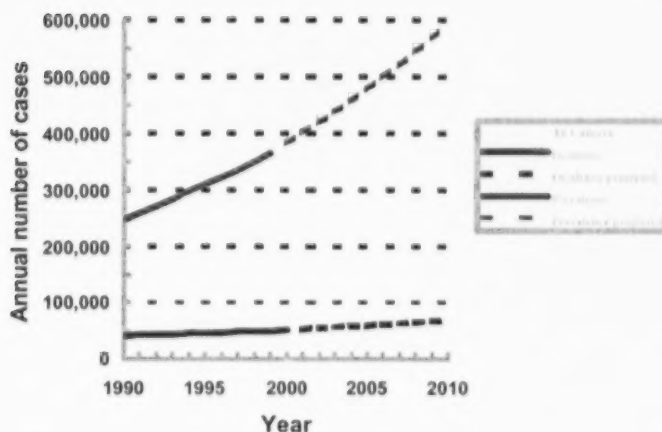
c) The Burden of Cancer in Ontario

Cancer creates a high burden of suffering and cost for Ontario. The frequency of newly diagnosed cases is growing at the rate of almost 3% per year. However, the number of people still living who were previously diagnosed with cancer is growing at over 4%. The increase in incidence is driven in part by the aging of the population and population growth.

Figure 1 illustrates the burden of new cases of cancer in Ontario and the projected number of incident cases for the next few years.

Figure 1: Actual and Projected Annual Incidence and Prevalence of Cancer in Ontario
(both sexes combined 1990 – 2010)

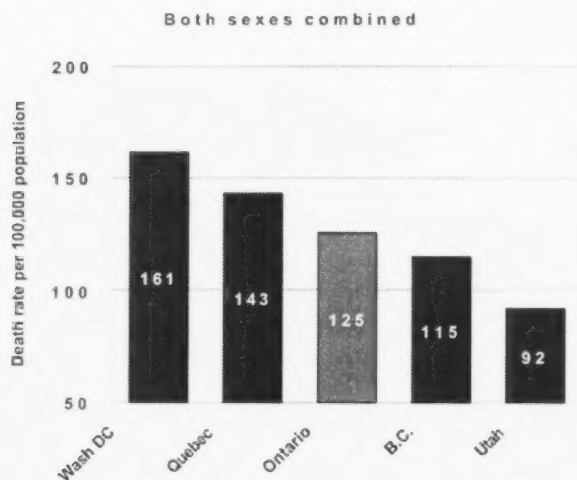
Annually, the frequency of newly diagnosed (incident) cancers is increasing exponentially at about 2.8% per year. For prevalent (still living and previously diagnosed) cases, the rate of increase is almost double, at 4.4% per year. By the end of 2010, we project an annual total of 68,000 newly diagnosed malignancies, and a prevalence of 594,000 cases. These projected counts represent increases of 70% and 140% respectively, from 1990 to 2010, for incidence and prevalence.



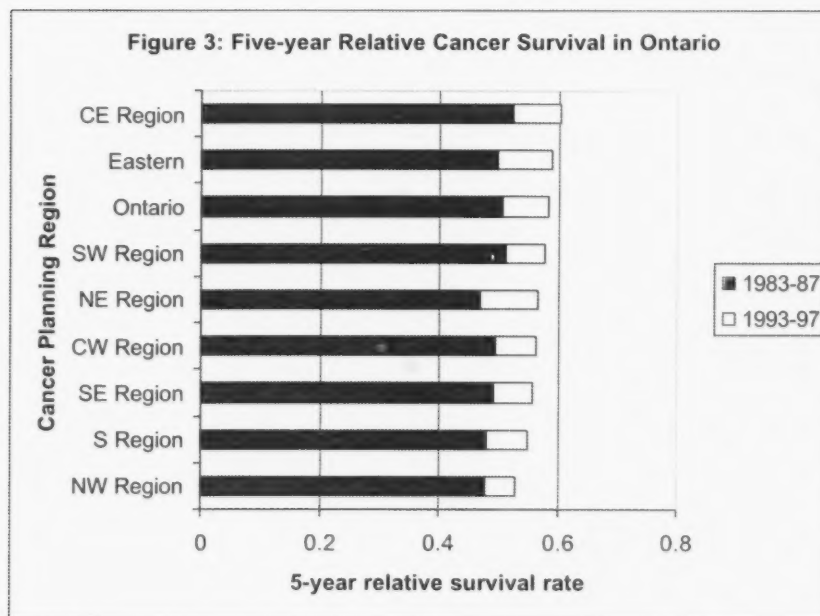
Source: Cancer Care Ontario (Ontario Cancer Registry, 2003)

With respect to death rates, based on comparable North American jurisdictions, Ontario is in the middle overall. (See figure 2.) With respect to cancer survival, Figure 3 shows how Ontario has achieved substantial improvement in the period from 1988 to 2000. Significant regional variation in the length of time patients live with the disease occurs for a range of reasons, including differences associated with socioeconomic status, treatment approaches and regional differences in the extent of the disease when patients first seek treatment.

Figure 2: Cancer Death Rates in North America, 1995-1999



Source: Cancer in North America (CINA) 2002. Age-standardized to world standard population



Source: Cancer Care Ontario (Ontario Cancer Registry)

From an economic standpoint, cancer is an expensive condition. According to the latest available information on traceable cancer costs (1998), Ontario spent over \$1.26 billion to treat the disease.³ The indirect costs of cancer (those costs associated with short and long-term disability and lost productivity) for that same year were estimated to be \$ 4.4 billion.

d) Ontario's Cancer System

In Ontario, cancer services are provided within a large and complex delivery system, characterized by a high degree of fragmentation. Many different organizations provide services to patients and a multitude of managers oversee different aspects of the system. Interestingly, only 30% of traceable provincial spending for cancer flows to the most visible cancer service providers: Cancer Care Ontario (approximately 23%) and Princess Margaret Hospital (approximately 7%). The remaining 70% of the cancer budget is provided to hospitals and community-based services largely through global budgets, which pay for diagnostic services and cancer-related surgery. Remarkably little is known about the majority of cancer services and this presents a serious challenge for quality and accountability in cancer care.

2. Supports for Quality Improvement

a) Health Quality Councils and Public Reporting

The Cancer Quality Council of Ontario is unique in its focus on quality for health care within a single disease as opposed to assessing quality in an entire health care system. The council has the opportunity to learn from and improve on the experiences of health councils in other jurisdictions.

In the past few decades, independent councils with overall responsibility to monitor the quality of health care systems and to guide change have emerged internationally in developed countries such as the United Kingdom, the United States and Australia. In Canada, interest in health care quality assurance led the Romanow Commission to recommend the formation of a national health council.⁶ The national council would establish indicators of performance, promote quality improvement efforts and report publicly on how to improve access and quality.

Some provinces already have quality councils as formal structures to systematically examine the quality of services. For example, in Saskatchewan, the Health Quality Council was established in 2002 as an independent agency that reports on and recommends ways to improve the quality of the provincial health system. In Ontario, there have been several proposals for a provincial health quality council,⁷ however, none of these has been implemented.

The advantages of these international and Canadian models include the potential for objective public reporting on quality and the focusing of responsibility for quality within a single body. In practice, however, the work of existing councils has been impeded to some extent by a lack of reliable and valid data for measuring quality. This is also a challenge for the CQCO.

Opportunities for Improving Public Reporting

- ✓ Develop a core set of system quality indicators for the Ontario cancer service system.
- ✓ Align these system-level indicators with emerging provincial and national reporting requirements.

b) Clinical Practice Guidelines

Clinical practice guidelines provide up-to-date statements on cancer care options based on the latest scientific evidence. They are an essential element of a quality cancer control system.

Cancer Care Ontario's Program in Evidence-based Care (PEBC) is a significant contributor to the ongoing quality mandate of the Ontario cancer system. One of its key contributions is the development of evidence-based clinical practice guidelines for oncologists through its Practice Guidelines Initiative (PGI).⁸ The program's clinical practice guidelines serve as benchmarks of quality, standards of practice and a foundation on which funding decisions for chemotherapy drugs are made.⁹⁻¹⁰

The PEBC involves over 200 clinicians who participate on guideline development panels and over 1,200 who act as external reviewers for draft documents. To date, there are 75 completed PEBC guidelines and 99 guidelines in progress. In addition to clinical practice guidelines, provincial disease site groups also develop evidence summaries used in cases where the evidence is not strong. The summaries are syntheses of the available evidence, accompanied by expert interpretation, to assist clinical decision-making to the extent possible.

The most established link between the clinical practice guidelines and clinical policy is through the New Drug Funding Program (NDFP), whereby PEBC guidelines are used by CCO's policy advisory committee to make recommendations regarding which chemotherapy agents should be funded.

The PEBC has studied the correspondence between guidelines and clinical behaviour. For example, a chart audit study was completed of the use of adjuvant chemotherapy in colon cancer with reference to guideline recommendations. Concordance with guidelines was greater than 90%.¹¹ The program has also been involved in studies of chemotherapy use for head and neck cancer,¹² patterns of radiation practice for women with breast cancer who have undergone lumpectomy¹³ and the impact of radiation waiting times.¹⁴

Opportunities to Strengthen Clinical Practice Guidelines

- ✓ Develop new methods to adapt and improve the efficiency of existing systematic reviews.
- ✓ Continue to capitalize on strategies to assess the impact of guidelines on clinical practice and policy.
- ✓ Expand work to test and evaluate strategies to promote the uptake of clinical recommendations into practice.

c) Population Databases

Ontario possesses a number of population databases, survey databases, a well-established cancer registry, research data files and raw data in charts. These are all important tools that can help assess a range of cancer service activities and it is important that Ontario take advantage of these data sources to measure quality.

Existing population-wide data sources are very attractive for health services research and quality assessment because they are more readily accessible and less expensive sources of information than data located in hospital, patient charts and doctors' offices. However, vital information may be missing or of poor quality. In addition, the interpretation of information from these databases, which were originally designed purely for administrative purposes, requires a high level of understanding of the database structure and elements, and highly competent analysts to do the job. Such individuals are in short supply.

Examples of the types of cancer quality information that are extractable from existing data sources include:

- rates of participation in organized breast cancer screening, and accuracy of tests;
- utilization, volumes, outcomes and waiting times for cancer treatments; and
- utilization of most palliative care services.

Notable gaps include:

- routine province-wide information on cancer risk factors;
- accurate data on utilization of colorectal cancer screening procedures;

- information on quality in diagnostic services, especially waiting times;
- reliable information about stage of cancer (the extent of cancer present at diagnosis); and
- supportive care utilization.

In general, these gaps exist because many of Ontario's databases record the date and type of service, but do not include result or outcome information. In addition, the completeness, quality, validity and reliability of all variables are not uniform across databases. Most databases contain anonymous information on individual cancer patients; some contain only information on groups of cancer patients. Moreover, few databases are available for analysis within one year of service delivery or health event. The lack of population samples with health-related quality of life outcomes and/or patient satisfaction is a major gap in Ontario's data.

Currently, health regulators are reluctant to approve linkage of databases by health card numbers. In fact, the Government of Ontario has refused to allow routine linkage of the Ontario Cancer Registry to administrative databases such as those held by the Ontario Health Insurance Plan, the Ontario Drug Benefit Program and others. This is a major barrier to quality measurement. This situation may improve in the future; however, it may also be possible that existing linkages are considered privacy violations and disallowed by legislation.

Opportunities to Strengthen Population Databases

- ✓ Develop and collect higher-quality stage specific cancer information in Ontario in order to make sense of mortality and survival through a range of variables, including treatment techniques.
- ✓ Develop electronic pathology reporting to the Ontario Cancer Registry to give the timeliest picture of when cancer was first diagnosed.
- ✓ Develop better information linkages between the diagnoses of cancer, (available only through the Ontario Cancer Registry), the data encounter and billing databases held at the Institute for Clinical Evaluative Sciences.
- ✓ Communicate the results of quality assessment and undertake action to improve the quality of cancer services.

- ✓ Ensure that databases are analyzed by highly competent analysts who can provide valid interpretations.

d) Cancer Informatics

Obtaining quality in cancer control will depend on informatics – the understanding and effective utilization of information technologies and information to improve the acquisition, storage and use of information to improve clinical care and enhance performance measurement.

In order to address the increasing burden of cancer, the cancer system requires innovative technologies as well as timely application of research and scientific breakthroughs. CCO, in collaboration with cancer system stakeholders, has developed a multi-year strategy to improve its ability to collect, analyze and disseminate data and information so that the resulting knowledge is used in both clinical and health services decisions. This plan can only be implemented through the concerted efforts of a coalition of partners across the cancer system.

So far, CCO has obtained broad support for the strategy, moved forward on implementing key information management initiatives, established integrated cancer programs and increased the awareness and importance of information management. Key challenges include the ability of the coalition partners to influence the many different organizations that oversee pieces of the system; the ability to overcome issues around privacy and consent of information and the ability to obtain sufficient investment to implement the plan.

Opportunities to Strengthen Cancer Informatics

- ✓ Integrate health records while at the same time protecting privacy and confidentiality of cancer patients.
- ✓ Establish comprehensive data sets with common data standards to support practice reviews, peer comparisons, research and outcome evaluation.
- ✓ Implement an information technology infrastructure to support information management strategy initiatives.

B. Key Indicators

1. Primary Prevention of Cancer

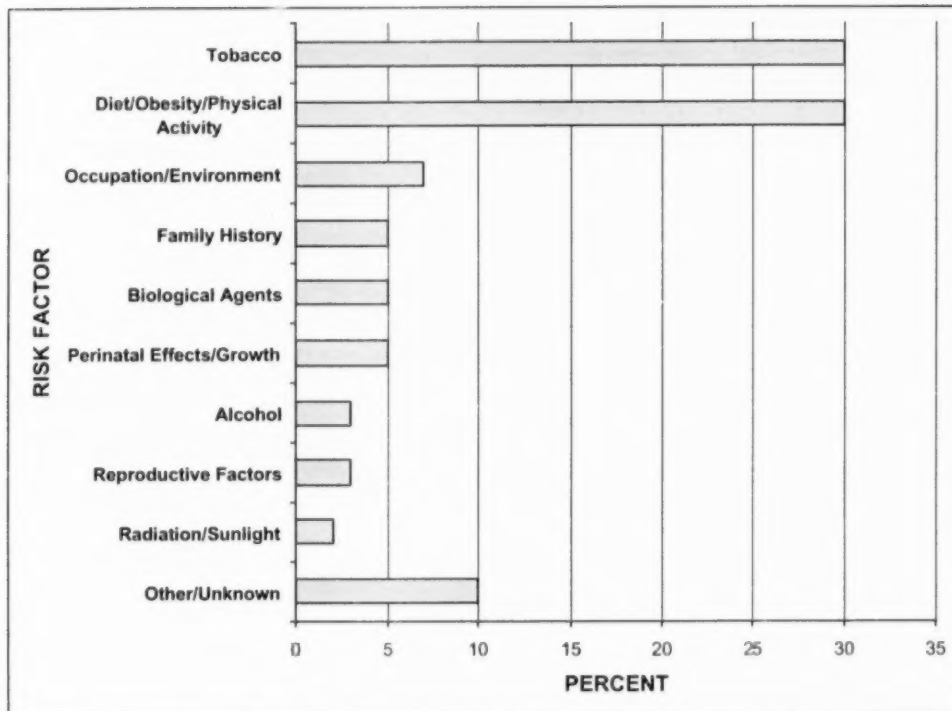
Cancer prevention is an important element of the provincial strategy for cancer control. It is estimated that at least 50% of the cancers that will be diagnosed over the next twenty years can either be prevented or detected early before becoming a serious health problem. A good quality monitoring system will require an ambitious cancer prevention plan including a surveillance program that would report publicly on progress toward that plan.

There is a strong and well-researched body of literature describing the many different causes of cancer. For example, more than half of all cancers can be linked to tobacco use, poor diet, physical inactivity and obesity. In addition, occupational and environmental factors, family history, alcohol use, sexual activity, infections and exposure to radiation and sunlight can play a large part in the development of cancer. Cancers that are easily prevented include the vast majority of lung cancers, most fatal skin cancers and some gastrointestinal cancers. Figure 4 describes the major causes of all cancer deaths in developed countries.

An even more compelling picture emerges about the relationship between certain risk factors and specific types of cancer. For example, approximately 90% of lung cancer in men and 80% in women may be caused by tobacco use.^{15 16} Lack of exercise may be a factor in 30 to 40% of breast cancers, 40 to 50% of colon cancers and up to 30% of prostate cancers.¹⁷

Research has also shown that the period between behaviour change and lowered cancer risk differs from other diseases. While the risk of coronary heart disease is cut in half after only one year of quitting smoking, ten years later, depending on how long an individual smoked, his or her risk of developing lung cancer is still higher than for people who never smoked.

Figure 4: Causes of Cancer Deaths in Developed Countries



Source: Adapted from Adami et al., 2001 and Colditz et al., 1996¹⁸

National, provincial and local surveys including the Ontario Health Survey, the National Population Health Survey, the Canadian Community Health Survey, and the Ontario Public Health Rapid Risk Factor Surveillance System Surveys have been used to provide snapshots of the prevalence of risk factors in Ontario's population. Regrettably, these types of surveys are currently not repeated frequently enough on a province-wide basis to provide reliable information on the impacts of interventions. Moreover, data from these surveys cannot be linked easily to other relevant databases and this impedes the ability to understand the impact of behaviour change and other interventions on cancer incidence.

The greatest opportunity for reducing modifiable cancer risks lies in a population-based approach. This approach uses comprehensive strategies to increase knowledge among the

public and health professionals and creates supportive environments that reinforce positive behaviour change across an entire population. Elements of a comprehensive strategy include research, policy change, collaborative partnerships, targeted media campaigns and media advocacy, educational and community-based programs, and monitoring and evaluation mechanisms.

The value of a comprehensive approach is especially evident in the area of tobacco control. A range of interventions has been shown to achieve results and data is now available on how much expenditure is needed to get a population-based response. For example, an effective 'dose' in the range of \$5 to \$16 per capita has been put forward as the minimum required to achieve a significant population-based reduction in tobacco consumption.¹⁹ In contrast, Ontario spent \$1.53 per capita on tobacco control in 2001/2002,²⁰ far short of what is needed.

The system for the primary prevention of cancer is broadly-based and involves many collaborators including the Canadian Cancer Society, local boards and departments of health, primary health care providers, educational institutions, workplaces, environmental organizations, advocacy groups and coalitions, multiple government sectors, CCO and others.

The recently released *Cancer 2020 Report: Targeting Cancer: An Action Plan for Cancer Prevention and Detection* presents a long-term strategy for cancer prevention in Ontario. Endorsed by the Minister of Health and Long-Term Care, it provides a framework that can be used to organize and develop efforts in prevention. *Cancer 2020* identifies a number of priorities including the establishment of a provincial cancer prevention and screening council. It proposes an evaluation framework that would include resource inputs, intervention strategies, impacts and outcomes and a solid data-gathering plan to measure each of these dimensions.

Opportunities to Improve Quality Monitoring of Primary Prevention of Cancer in Ontario

- ✓ Take full advantage of the existing body of evidence on primary cancer prevention in the development of effective interventions.
- ✓ Develop a regular, periodic (or continuous) survey of risk factor prevalence, which is Ontario wide and includes appropriate regional summaries.
- ✓ Establish a provincial prevention and screening council and start the development and execution of strategies to change population risks.

2. Cancer Screening

The purpose of screening is to detect cancers or cancer precursors early, before they present with symptoms, leading to early detection, more effective treatment and a decreased likelihood of death. The purpose of cancer screening is to reduce mortality rates for populations who access screening. Improved quality monitoring of cancer screening is possible in Ontario with the establishment of better systems for data collection and assessment.

The Canadian Task Force for Preventive Health Care Screening has ranked screening tests for cancers of the breast, cervix and colorectum as having good or fair evidence. Ontario has been providing organized cancer screening for breast cancer for over ten years, however, programs for cervical and colorectal cancer screening are in early stages of development.

Most screening in Ontario is delivered in an unorganized fashion. That is to say screening typically occurs when patients are visiting their doctors for unrelated problems. For example, a Pap test may be performed on a woman who visits her doctor about an unrelated medical ailment. This presents a challenge for quality assessment. Organized screening programs can improve factors such as the recruitment of participants, quality assurance, retention of participants (i.e. regular attendance for screening), assessment procedures and the time to investigate abnormal screens, whether benign or malignant, and client outcomes.

Ontario's first widespread organized screening program, the Ontario Breast Screening Program (OBSP), was introduced in 1990. Planning has been underway for population-based colorectal cancer screening since 1998, when emerging scientific evidence pointed to a mortality benefit from routine colorectal screening. A pilot study on how best to implement population-based colorectal cancer screening in Ontario was announced in June of 2003 and results are expected by January of 2005.

A thorough evaluation of screening requires data on test utilization and results, follow-up diagnostic procedures, final outcome results and population-based data. These requirements can only successfully be met through an organized approach to screening. Unfortunately, however, there are significant barriers to sharing data between different custodians in Ontario and CCO has access to very few of the data sets required to complete a comprehensive assessment of various kinds of cancer screening.

The OBSP collects data to support regular evaluation of quality. National targets have been developed for breast screening, which the OBSP uses to monitor the quality of its program. Similar quality data for screening outside of the OBSP are currently not available. In addition, quality indicators for cervical screening have been developed by CCO, however there is much less data available to support quality measurement. Moreover, national targets for these indicators have not been developed. Finally, it is currently impossible to report on the quality of colorectal screening services since OHIP does not distinguish screening procedures from symptomatic investigations of the colorectum.

It is estimated that approximately 5 to 10% of all cancers are associated with predisposing genes that increase an individual's risk of developing cancer. Ontario has been a leader in the introduction of screening for heritable breast, ovarian and colorectal cancers. Individuals considered to be at increased risk for an inherited cancer can be referred by a physician to a regional genetics clinic. Quality indicators for genetic screening services are in the early development phase.

Opportunities to Improve Quality Monitoring of Cancer Screening Services in Ontario

- ✓ Promote population-based cancer screening according to evidence-based screening guidelines and recommendations.
- ✓ Consolidate breast cancer screening and assessment data from both the Ontario Breast Screening Program (OBSP) and other fee for service sources.
- ✓ Establish billing codes for screening procedures as distinct from diagnostic tests.
- ✓ Develop quality indicators for colorectal cancer screening.
- ✓ Enhance Ontario's genetic screening services through program evaluation, quality indicator development and the timely collection of genetic screening data.

3. Cancer Treatment

Maximizing the effectiveness of treatment requires that effective forms of treatment are made available and delivered correctly to all those who need them. To maximize the societal benefits of cancer treatment, active steps must be taken to optimize the quality of care and ensure adequate access to care.

Cancer treatment has a major impact on the societal burden of cancer. The estimated mortality from cancer in Canada in 2003 (67,400) was approximately 50% of the estimated incidence (139,900) largely because many patients with common cancers are cured by conventional treatment with surgery, radiotherapy and/or chemotherapy.²¹ Moreover, cancer treatment further reduces the societal burden of cancer by alleviating symptoms, maintaining function and prolonging survival among patients with incurable cancers. Thus treatment is an important aspect of cancer control and is likely to remain so for the foreseeable future.

a) Surgery

Approximately 80% of patients who develop cancer will require surgery²² and the quality of surgical care directly influences clinical outcomes and the subsequent care pathway. Surgical oncology is a new frontier for quality assessment.

Cancer surgery in Ontario takes place in a variety of settings and is practiced by general surgeons, sub-specialty surgeons (gynecologists, thoracic surgeons, urologists) and surgical oncologists affiliated with tertiary care teaching hospitals. The majority of inpatient and same-day cancer surgery is performed in community hospitals (72%). The remainder is performed at hospitals associated with cancer centres (22%) or at the Princess Margaret Hospital (6%).²³

Cancer Care Ontario has been working to develop an integrated system of surgical oncology practitioners in community and teaching hospitals and cancer centers. A surgical oncology presence was established in all regional cancer centers in 1998 and cancer surgery networks were created to encourage multidisciplinary consultation and treatment. Referral networks have been organized to deliver specialized surgical care for as gynecologic cancers, ocular cancers and musculoskeletal cancers.

There have been few investigations of access to and appropriateness of cancer surgery in Ontario and there are virtually no quality indicators for cancer surgery. Table 1 describes the current state of knowledge about cancer surgery.

Table 1: Quality Indicators for Cancer Surgery

Access	There has been minimal investigation of the overuse or under use of cancer surgery and associated processes. Information on waiting time trends in Ontario from 1990 to 2001 is pending.
Outcome	The relationship between the volume of activity and the outcome of pancreatic cancer surgery is abundantly clear, however evidence of a relationship for other cancer types is contradictory and requires systematic review. Few population-based cancer surgery outcomes have been investigated. Length of stay, readmission, surgical mortality, recurrence and survival can be determined using hospital discharge data. Disease-specific indicators (e.g. complications, quality of life) should be measured at a system level to reflect the complex nature of multi-disciplinary care.
Appropriateness	Research is required on appropriateness and consistency with clinical practice guidelines for surgery.
Variations	Variations have been documented in several studies related to cancer care. Few such studies have been carried out in Ontario.

Opportunities to Improve Quality Monitoring of Surgical Programs in Ontario

- ✓ Develop indicators to measure quality of cancer surgery throughout the province and for all disease sites, including those that measure access, appropriateness, waiting times, volume-outcomes and clinical and health-related quality of life outcomes.
- ✓ Develop standard waiting time targets for cancer surgery.
- ✓ Monitor these quality indicators on a regular basis and address variations in care.

b) Radiation

Regional radiotherapy clinics were the foundation of what is now CCO. Unfortunately, access to RT is inadequate and its quality needs to be monitored more closely. Quality assurance programs need to be enhanced and extended to include evaluation of outcomes as well as structures and processes.

Radiotherapy (RT) is one of the most important and widely used conventional treatments for cancer.²⁴ RT is an essential element of the curative treatment of many types of localized cancers and it is also effective in alleviating the symptoms of many patients with advanced cancers. In most situations where it is used today, the effectiveness of RT has been demonstrated in well-designed randomized trials and outcome studies.²⁵

The nature of RT makes scrupulous quality assurance absolutely essential and maximizing the benefits of RT in the individual patient requires a high degree of accuracy in its planning and delivery. In theory, RT is targeted and delivered in such a way that it causes a necessary degree of damage to the cancer without causing unacceptable damage to the surrounding normal tissues. However, the practice of RT is highly complex and vulnerable to error. Every treatment plan must be made to measure and this limits the extent to which processes can be standardized. Optimal outcomes often require a high degree of precision. RT is a multi-step process involving very complex equipment that must function correctly and be operated carefully to avoid error.

In Ontario today, there are well-defined technical standards for the operation of RT equipment and facilities, and well-established guidelines, developed by the Healing Arts Radiation Protection (HARP) Commission of Ontario for quality assurance in RT programs.²⁶ Although there is no evidence of any major problem in the technical quality of RT in Ontario, there is no central oversight carried out of the quality assurance programs in RT centers in Ontario. At present, the responsibility for quality assurance rests entirely with individual treatment centers.

There have been extensive efforts to make RT widely accessible through the creation of a provincial network of RT centers however, access to RT in Ontario today remains inadequate and inequitable among regions. Over the past two decades, demand for RT has

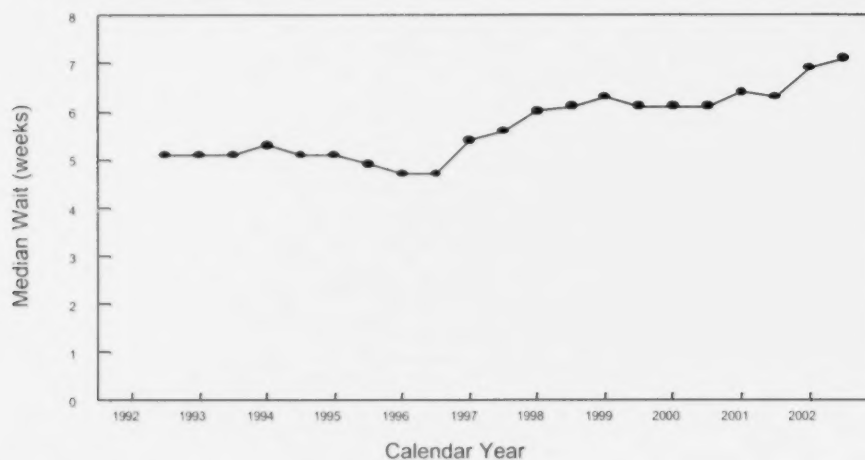
increased, partly due to the discovery of new indications for RT and partly due to the increasing incidence of cancer that is a consequence of an aging population.²⁷

Detailed reports of waiting times are regularly compiled by CCO and made available to all provincial RT programs. Figure 5 shows trends in waiting times for all types of cancer combined, at all CCO-operated RT centers over the period 1992 to 2002. The increase in overall waiting times since 1996 reflects increases in both the waiting time for consultation and the waiting time from consultation to start of treatment.

Figure 5

Note: The graph shows the trend in the waiting time from referral to a cancer centre to the start of RT for all cases of cancer treated at a centre operated by Cancer Care Ontario over the period 1992-2002. The data points represent the median waiting times over the corresponding six-month period. These graphs are based on data that are routinely available to all treatment centres on CCO's intranet.

Temporal Trends in the Waiting Time from Referral to Start of Radiotherapy



At present, the Canadian Association of Radiation Oncologists (CARO) recommends that the delay between referral and consultation should not exceed two weeks and that the delay between consultation and start of treatment should not exceed an additional two weeks. In general, average waiting times exceed the CARO recommendation.

The proportion of patients treated with RT varies widely across the province and some patients who might benefit from RT may not be treated at all. In general, where waiting lists for RT are longer, the proportion of cases that receive RT is lower. Lower rates are also observed in areas that lie further away from the nearest RT center. Comparison of the observed rate of use of RT in Ontario with the estimated appropriate rate has revealed that up to 20% of Ontario residents that should receive RT do not currently get it.

Opportunities to Improve Quality Monitoring of Radiotherapy Services in Ontario

- ✓ Ensure that all cancer centers comply with the guidelines for quality assurance of the Healing Arts Radiation Protection (HARP) Commission of Ontario.
- ✓ Conduct an independent, external review of Ontario's RT system to advise the government on the status of the RT system and the adequacy of plans to enhance its capacity and performance.
- ✓ Develop a comprehensive plan to address the problem of inadequate access to RT in Ontario.

c) Systemic Therapy

Cancer Care Ontario has made significant strides in ensuring high-quality systemic therapy in cancer. Where regimens have clear indications for use, there is value in determining whether those who should benefit from these treatments do so.

Systemic therapy includes chemotherapy, as well as hormones, immune therapies, vaccines and molecular targeted therapies that circulate throughout the body's systems to attack cancer cells wherever they are located. Its use in Ontario for patients with cancer is increasing at an annual rate of 11%, which is far greater than the rate of increase in the number of cancer patients overall. About half of patients with cancer receiving systemic therapy are seen at the Princess Margaret Hospital or within CCO-affiliated regional cancer centers. The others are seen in a variety of community hospital and private office settings.

Any physician in Ontario may prescribe oral anti-cancer drugs and supportive medications. These may be paid for by patients themselves, by third party insurers, through hospital global budgets and through the Ontario Drug Benefit Program (ODB) for patients over 65 years

old, for those on social assistance or for those who are uninsured and spend more than roughly 4% of their income on medications. In 2001-2002, approximately \$75 million was spent by ODB on oral or subcutaneously administered anti-cancer drugs. Private payers spent an additional \$40 million, raising the total value of oral anti-cancer drugs and supportive medications to \$115 million.

Waiting times to access chemotherapy has increased at an average rate of four days per year since 1999, due mostly to an increase in the waiting times to get a consultation with a medical oncologist.²⁸

At this point in time, electronic physician order entry is in place mainly in the CCO regional cancer centers. This technology not only facilitates chemotherapy administration, it is also an important quality assurance tool because computer-aided standardization of chemotherapy ordering enhances safe practice and reduces the risk of human error.

An additional important quality management tool is the monthly drug utilization review carried out by region, by clinic or even by individual physician according to disease type and stage. This review allows identification of practice variability and guideline concordance.

Cancer Care Ontario currently oversees the New Drug Funding Program (NDFP), which manages the introduction of, and reimbursement for new and expensive cancer drugs in Ontario. This program currently has a budget of over \$47 million²⁹ and includes 15 drugs for 28 indications, representing 70% of the IV chemotherapy used in Ontario and approximately 30% of total chemotherapy use. Beyond this program, CCO has minimal influence on the use of oral agents and little knowledge of chemotherapy administered in hospitals.

Through the NDFP, CCO is able to determine how most intravenous chemotherapy is used and can generate a great deal of information about the appropriate use of these treatments. CCO's Program in Evidence-Based Care (PEBC) requires that reimbursement of drug costs to hospitals be dependent on use according to pre-established criteria based on clinical practice guidelines. In 2002 a formal audit of the program revealed a high degree of concordance with established use criteria.

Opportunities to Improve Quality Monitoring of Systemic Therapy in Ontario

- ✓ Continue to develop clinical practice guidelines and supportive information systems.
- ✓ Establish a single cancer drug formulary and reimbursement program that integrates oral and intravenous anti-cancer drug use.
- ✓ Expand computerized physician order entry beyond CCO to other hospitals providing systemic therapy.
- ✓ Develop standard operating procedures governing the use of chemotherapy and require adherence as a condition of drug cost reimbursement under the NDFP.
- ✓ Develop standard waiting time targets for systemic therapy.
- ✓ Develop objective measures to assess access to care, appropriateness and costs and assess performance against these measures at regular intervals.

4. Supportive Care

Supportive care services are designed to meet the physical, informational, emotional, psychological, social, spiritual and practical needs³⁰ of people living with or affected by cancer. Measuring quality performance indicators in supportive care is a new endeavour both in Ontario and also in other jurisdictions.

The primary focus of supportive care is on integrating person-centered approaches within the existing tumor-centered treatment delivery approach. Ideally, supportive care should take place during the entire cancer experience including diagnosis, treatment and follow-up. It also encompasses issues of survivorship, recurrence, palliative care and bereavement.

Cancer and its treatment bring a myriad of emotional, psychological, social and spiritual consequences. Its experience creates substantial changes in the lives of individuals and their families. If supportive care needs remain unmet, patients continue to experience on-going emotional distress and upheaval. This distress can escalate and affect compliance with tumor therapy, which may result in greater use of other health care services.

There is a growing awareness within the provider community and amongst the public of the need to address a broader range of patient needs and involve patients in decision-making about their care. These needs include but are not limited to effective coping with cancer, long-term survivorship and access to palliative care.

Unfortunately, the range of services and collaborative partnerships required to meet the supportive care needs of cancer patients and their families are in short supply across Ontario. Programs remain unevenly distributed and in many settings, the required interdisciplinary team does not exist.³¹ Most cancer programs do not have an appropriate complement of staff to meet the full range of patient needs. Overall, less than 3% of cancer program budgets are clearly allocated to supportive care. Currently, less than 5% of Canadians have access to palliative care.³² Although pockets of excellence exist and progress has been made in some settings, there are significant improvements required to provide appropriate levels of supportive care throughout Ontario.

A concerted effort is needed in Ontario to create performance indicators about supportive care. To date, the primary focus of quality efforts in the supportive care field has been on

the development of standards for patient care. These standards are at various stages of implementation across the country and are seen as the first step toward defining and measuring quality. A secondary focus has been on the development of practice guidelines for specific patient problems (e.g., lymphedema, breathlessness, pain, depression, psychosocial distress) and clinical pathways for specific patient groups (e.g., psychosocial care of women with breast cancer). These tools help describe expectations for care delivery based on levels of evidence. Implementation and evaluation of impact have not yet occurred.

The cancer system does not regularly collect or analyze information about the quality of supportive care, but there are a handful of initiatives underway to remedy this situation. The CCO Provincial Supportive Care Program Committee has initiated a process to identify quality performance indicators for supportive care. The CCO Provincial Supportive Care Program Committee has defined five types of benchmarks for development. These are summarized in Table 2. Actual quantitative targets or benchmarks from which to measure performance in supportive care in these domains have yet to be established.

Table 2. Supportive Care Quality Indicator Measurement in Ontario

Domain for Benchmark	Key System Performance Indicator	Data Currently Available	Recommendation
Burden of Suffering	% of patients with a specific need for supportive care intervention. Focus: ▪ pain ▪ emotional distress	▪ No system-wide data in existence ▪ Available data within research projects only	▪ Develop and implement standard/guideline concerning assessment and documentation of two variables: pain and emotional distress ▪ Incorporate variables into minimum dataset for reporting purposes
Adoption of Standards	Continuity of Care	▪ No tool currently exists to collect data	▪ Establish research working group to develop/test measurement tool
Human Resources	# qualified staff available in system	▪ can identify # staff in regional cancer centres	▪ Establish mechanisms to document and track cancer supportive care staff across Ontario
Access to Service	% accessing psychosocial oncology services	▪ CCO has supportive care patient activity	▪ Extend implementation of patient activity to other regional cancer programs

Domain for Benchmark	Key System Performance Indicator	Data Currently Available	Recommendation
	% accessing palliative care service	reporting tool (6 RCCs) with ability to collate to provincial level	▪ Report % patients who access supportive care services
Patient Satisfaction	% patients satisfied with patient-centred nature of care	Patient satisfaction survey developed and validated. In process of implementation.	▪ Use supportive care items on patient satisfaction tool for provincial reporting

Opportunities to Improve Quality Monitoring of Supportive Care in Ontario

- ✓ Obtain broad commitment to integrated supportive care for cancer patients and their families in Ontario.
- ✓ Reach agreement on key supportive care indicators across the spectrum of cancer care.
- ✓ Develop and test measurement tools for key indicators.
- ✓ Obtain dedicated resources to conduct the necessary work (information systems, clinical resources, research resources).

C. Examples of activities that would improve the quality of cancer services

1. Patient Safety

Patient safety is an important, visible and measurable component of quality cancer care. Efforts to improve patient safety will have an important impact on the quality of cancer care.

The nature of cancer interventions makes patient safety a critical issue in cancer care. Treatments often require high doses of potent agents and the use of other powerful therapies, alone or in combination and expose patients to significant risks for complications and adverse effects. Cancer patients are often managed by more than one physician and in more than one place, adding to the complexity of their care and to the inherent risk of error.

It has been pointed out that physicians and nurses have significant difficulties dealing with adverse events and human errors, because of the culture of medical practice.³³ Fortunately, modern views of human error have started to move away from individual culpability and the accompanying 'blame and train' response to the identification of patterns of events and the systemic causes that contribute to their occurrence. Consistent, reliable non-punitive reporting of adverse events and errors is fundamental to improving patient safety.

Currently literature is limited on patient safety initiatives in cancer care and, in Ontario, there is no province-wide, integrated strategy to monitor adverse events, errors or quality of process or outcomes in cancer care. Patient safety efforts in Canada lag behind those in Australia, the United Kingdom and the United States where important initiatives are underway to identify adverse events and improve the safety and quality of patient care.

Improvement in the design of the systems in which cancer care is delivered can decrease the likelihood of adverse events and patient harm. In Ontario, there is inconsistency in both the definition and reporting of adverse events and no mechanism to share information between sites. There is no policy related to disclosure of adverse events. However, quality monitoring systems related to patient safety are being developed and there initiatives are

emerging to deal with these issues. Some individual programs and hospitals have developed reporting and monitoring systems with varying degrees of sophistication and effectiveness.

Opportunities to Improve Quality Monitoring of Patient Safety in Ontario

- ✓ Encourage the reporting of adverse events and identify ways to improve care and promote learning so that errors are less likely to be repeated.
- ✓ Improve the measurement of adverse events and activities associated with them.
- ✓ Implement change strategies to create care environments that are less likely to result in harm. These strategies would include changes in processes and technology such as computerized order entry systems.
- ✓ Improve health provider education and facilitate change in the culture of clinical practice and learning.

2. Oncology Nursing

Nurses assess, plan and intervene with care elements that address the multidimensional needs of those faced with cancer. The quality of care is influenced by the care delivery model in important ways and the expansion of nursing roles is required to meet the increasing needs of patients across the continuum of care.

Measuring the quality of oncology nursing requires a focus on structure, processes and outcomes of care. Key quality challenges include the aging nursing population; increasing patient acuity; increasing accountability for nursing practice; lack of workload measurement tools; absence of reliable nursing data recorded in administrative databases. As complexity of care increases and as the current workforce in nursing ages, aggressive recruitment and specialty education programs in all practice environments are essential.

Currently, there is a lack of data to track process-of-care indicators related to nursing interventions; however, there are initiatives underway to address some of the key issues facing the nursing profession. Advanced practice nurses have been introduced in oncology settings in both hospitals and ambulatory centers and the Ministry of Health and Long-Term Care is studying best practices. Symptom assessment tools have been introduced into regional centers and in hospital settings, workload measurement tools have been in place for some time.

Opportunities to Improve Quality Monitoring of Oncology Nursing in Ontario

- ✓ Support educational programs to increase the supply of well-trained oncology nursing staff.
- ✓ Develop reliable and valid workload measurement tools.
- ✓ Conduct outcome-focused research in areas such as workload measurement, nursing interventions and forecasting health human resource needs.

D. Summary: Assessing Cancer Quality in Ontario

Ontario's cancer control system and its providers are among the finest in Canada and are modeled by policy makers and health care planners throughout the world. A foundation already exists for quality assessment that includes evidence-based indicators and a variety of already established data collection systems. However, meeting the growing demand for cancer care will require an aggressive approach to a number of system challenges, information gaps and treatment issues.

- **Ontario already has a cancer system of reasonable high quality** with well-trained and dedicated health professionals. This system achieves health outcomes which are comparable to those of neighboring jurisdictions. Nevertheless, there are important quality gaps that require attention. These gaps are explored throughout the book.
- **Strengthening Cancer Research** in Ontario must be firmly embedded in comprehensive academic cancer service centers
- The Cancer Quality Council of Ontario has identified a number of areas where quality improvement efforts are needed and likely to have the greatest impact. These include the following:
 - Ontario has a great deal of data about cancer services and outcomes, however the inability to conduct regular linkages between service and outcome data bases compromises our ability to paint meaningful pictures of service quality. **Ontario needs to remove the barriers to health services research in the field of cancer.** In addition, **a cancer information system is needed** to monitor the performance of the cancer system and focus quality improvement initiatives.
 - **Prevention and screening are the best hope for reducing the epidemic of Cancer in Ontario.** Ontario has a long-term cancer prevention and screening plan (Cancer 2020) which sets out targets for changing behaviours that affect cancer risks. Strategies to reach the targets need to be developed, funded and implemented. Progress towards the targets set should be reported publicly.
 - **Many people in Ontario are waiting longer than recommended by expert bodies for major cancer treatments** and some people who could benefit from treatment after their initial surgery do not receive best practice. Wait times for all cancer treatment (surgery, radiation therapy and chemotherapy) have increased over the past decade.
 - **Routine monitoring and public reporting of performance is needed to drive quality improvement.** The CQCO is currently developing a valid and reliable set of quality indicators, capturing a number of aspects of cancer system performance including patient satisfaction, wait times, efficiency, outcomes – all necessary to close the gap between the demand for and supply of health care services.

Conclusion:

Charting a Course for Quality Improvement

This synopsis has highlighted the major quality improvement opportunities that currently lie ahead for cancer control in Ontario. Although a course has been charted for areas that require improvement in cancer control today, it is important to note that the voyage must take place in the rough and unpredictable waters of an ever changing and dynamic Canadian health care system.

The level of quality cancer control that is set must be ambitious and achieving it will require the active partnership of many individuals and organizations. These partners include Cancer Care Ontario, Princess Margaret Hospital, hospitals providing regional and local cancer services, laboratories, community service providers, primary care practitioners, public health units and others such as the Canadian Cancer Society. The journey will be guided by data custodians who track quality information such as the Institute for Clinical Evaluative Sciences, the Canadian Institute for Health Information, the Joint Policy and Planning Committee and the Program in Evidence Based Care.

In addition, effective approaches to cancer quality will require very significant research commitments to develop, monitor and improve quality in the cancer system. Careful integration of research into all aspects of the cancer system is fundamental to long-term quality.

The establishment of the Cancer Quality Council of Ontario by the provincial government is a bold initiative that will lead to significant improvements in the quality of cancer services for the people of Ontario. As Cancer Care Ontario achieves its goal of a comprehensive and coordinated cancer system by integrating regional cancer centers with host hospitals, opportunities will emerge to deliver ever-improving quality standards and increasing levels of efficiency and thereby ensure the highest possible quality in all cancer services in Ontario. In particular, the development of quality indicators and annual reporting on these will be an immediate next step from the Cancer Quality Council of Ontario.

Individuals and groups are invited to comment on this report. The Cancer Quality Council of Ontario counts on your support as it moves forward with an ambitious quality agenda for all cancer services in Ontario. Please email the CQCO at qualitycouncil@cancercare.on.ca

Endnotes

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